

What's Going on @SPNS

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❖ Stigma and the SPNS YMSM of Color Initiative

The mark of shame is found everywhere, not just while dealing with HIV. It starts at home, where people damn the less fortunate for either having a poor education or struggling to make dead ends meet by any means possible.

The above words, spoken by an outreach worker whose job is to persuade young men who have sex with men (YMSM) to be tested for HIV and to access medical care, neatly captures how stigma can affect the work of those trying to slow the spread of the disease.

What is HIV/AIDS-related stigma? It consists of the unfavorable attitudes, beliefs, and policies directed toward people perceived to have HIV/AIDS as well as toward their loved ones, associates, and communities.¹ Often, HIV/AIDS stigma is expressed in conjunction with one or more other stigmas, particularly those associated with homosexuality, bisexuality, and injection drug use.

The existence of HIV/AIDS-related stigma has been widely documented.² For example, many people living with HIV/AIDS (PLWHA) suffer discrimination that can lead to loss of employment and housing, estrangement from family and society, and increased risk of violence. HIV/AIDS-related stigma also fuels new HIV infections because it can deter people from getting tested for the disease, make them less likely to acknowledge their risk of infection, and discourage those who are HIV positive from discussing their HIV status with their sexual and needle-sharing partners.

The health care system itself can be a source of stigma. The literature on caregiving reveals that stigmatization is evident among health care providers' attitudes toward and treatment of HIV-positive patients.^{3,4} Research shows that PLWHA are evaluated more negatively than people diagnosed with other incurable diseases, even by health care workers, and that caregivers commonly avoid PLWHA and overestimate the risks of casual contact with them.⁵ Moreover, health care professionals, particularly those who infrequently encounter PLWHA, can be insensitive to their patients' concerns about stigma and are not always knowledgeable about appropriate procedures for maintaining patient confidentiality.¹

Stigma related to HIV/AIDS extends beyond the disease itself to providers and even volunteers involved with the care of PLWHA. For example, some patients will switch medical providers when they learn that their provider is HIV positive or cares for PLWHA.^{2,6} Caregivers, whether professionals or volunteers, risk stigmatization as a result of their association with HIV/AIDS and PLWHA. That stigma may influence their willingness to work with PLWHA or may make their work more difficult.⁷

Stigma affects such issues related to HIV testing as delays in testing and individuals' responses to testing positive.⁸ Studies provide evidence that stigma is associated with delays in HIV testing among people who are at high risk of being infected with HIV.^{9,10} In a study of gay and bisexual men who were unaware of their HIV status, two-thirds of the participants expressed concerns about discrimination against people with HIV and said it was a reason for not getting tested.¹⁰ A 2000 Kaiser Health Poll found that one-third of survey respondents said that if they were tested for HIV, they would be "very" or "somewhat" concerned that people would think less of them if they discovered that they had been tested. In addition, 8 percent of people who had never been tested for HIV said that worries about confidentiality played a part in their decision not to have the test.¹¹

Stigma and the YMSM of Color Initiative

Clearly, stigma presents challenges for PLWHA who want to access medical care and for efforts to bring people at high risk for HIV into testing and care. It presents a particular challenge for the U.S. Department of Health and Human Services (HHS), Health Resources and Services Administration, HIV/AIDS Bureau, Special Projects of National Significance (SPNS) YMSM of Color Initiative, which is addressing the urgent problem of disproportionate HIV infection rates among YMSM. The initiative consists of eight 5-year demonstration projects targeting YMSM of color between ages 13 and 24. The projects are designed to reach members of the target population who



are not currently in care and link them with ongoing primary care, support, and prevention services. In addition, an evaluation center at George Washington University is coordinating the design and implementation of the demonstration project evaluations and will support the replication of models that are shown to be effective. The center is providing ongoing technical assistance to the grantees.

Among racial and ethnic minority men, sexual contact with other men is the primary cause of HIV infection; moreover, minority MSM appear to become infected at earlier ages than do Whites and learn that they are seropositive later in the course of infection.¹²

According to the HHS Centers for Disease Control and Prevention (CDC), YMSM, especially those of minority races or ethnicities, are at high risk for HIV infection. In the seven cities that participated in CDC's Young Men's Survey during 1994–1998, 14 percent of African-American MSM and 7 percent of Hispanic MSM ages 15 to 22 were infected with HIV—significantly more than the 3 percent of White MSM in that age group who were HIV positive.¹³

Although race and ethnicity are not themselves risk factors for HIV infection, the following social and economic factors are associated with increased HIV risk among young men of color:

- Stigma or fear of condemnation or discrimination
- Historically poor access to medical care
- Negative perceptions of the health care system
- Self-perceptions of sexual orientation
- Youth perspectives that make it difficult to assess risks and understand and adopt preventive behaviors

Each project funded under the YMSM initiative is addressing those barriers. Stigma is both a cause and consequence of barriers to medical care, and it is a particularly important challenge in the efforts of the YMSM grantees.

Stigma may be a greater barrier to providing services to YMSM of color than it is to adult populations because HIV-positive YMSM of color experience stigma in multiple ways: (1) They are HIV positive; (2) they are MSM; and (3) they are members of a minority group.¹⁴ In addition, youth itself can be a barrier to care, because the sense of invulnerability many youth have may make them reluctant to seek care or take steps to protect themselves from HIV transmission.¹⁵ Moreover, a YMSM of color may be rejected by his family if his sexual practices or serostatus become known. Other sources of support, such as church or school activities, may ostracize him, increasing his isolation. The organizations funded under the YMSM initiative are testing new strategies for providing information about HIV, reducing risk of HIV transmission, and bringing youth into medical care.

YMSM of Color Grantees

- Bronx AIDS Services, Bronx, NY
- Working for Togetherness, Chicago, IL
- AIDS Project East Bay, Oakland, CA
- Men of Color Health Awareness Project, Buffalo, NY
- Wayne State University, Detroit, MI
- Harris County Public Health and Environmental Services, Houston, TX
- University of North Carolina, Chapel Hill
- Los Angeles County Department of Health Services, Office of AIDS Programs and Policy
- George Washington University (Evaluation Center)

For additional information on the SPNS YMSM of Color Initiative, visit http://hab.hrsa.gov/special/ocp_index.htm. The SPNS Project Officers for the initiative are:

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Experiences on the Frontlines

Staff of the eight projects that compose the YMSM of Color Initiative, particularly peer outreach workers, deal with stigma both directly and indirectly. Peer outreach workers from each grantee site were recently asked how stigma affects their work. Their responses* reinforce the research findings on stigma's impact on bringing people into care.

The Role of Internalized Stigma: Workers and Clients

One recurring theme was that HIV/AIDS stigma affects not just the target population but also the outreach workers. Outreach workers must address their own feelings of self-worth before they can help others. Their comments illustrate this point:

I wonder how much easier growing up would have been for me had there been persons in my life who mentored and helped me along. . . . As community leaders and advocates, we have an opportunity to engage with youth in this capacity, showing by example how being gay, lesbian, bisexual, or transgender does not mean living a life filled with secrecy and shame.

Other workers observed how deeply stigma affects members of the target population:

[B]efore I can teach young MSM about HIV prevention, I have to teach them about self-love, self-appreciation. . . .

* Program staff provided their observations as part of a larger discussion of the barriers and challenges they face in their work.

In most cases I have to attempt to scale mountains of self-loathing and show them just because you're gay doesn't mean you're worthless.

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One worker noted that societal stigma is so pervasive that it interferes with the peer outreach mission:

I feel that sometimes fighting those misconceptions, fears, and/or ignorances people have about the MSM community gets in the way of the real work we're here to do. Instead of the work we are supposed to do, we get trapped defending ourselves, our friends, even our enemies, which is a great thing to do but it can distract us from what our true mission is. . . .

Impact on HIV Care

Stigma affects the care of PLWHA. As noted earlier, HIV/AIDS-related stigma influences individuals' responses to testing positive, in part because it aggravates the psychological burden of receiving a positive HIV test.⁸ Earlier in the epidemic, there were reports of severe psychological responses to learning of seropositivity, including denial, anxiety, depression, and suicidal ideation.^{16,17} Over time, studies have shown a decrease in such reactions, but research continues to show that notification is associated with high distress.¹⁸ These findings are reflected in the activities of the YMSM of color projects. For example, one peer outreach worker noted:

We recently had a newly HIV-positive African-American male 20 years old, who when asked by the youth health care provider what type of sexual contact he had engaged in, responded by yelling at the provider, "I'm not gay!" This young man resisted accessing support services offered to him due to a fear of being labeled as gay. This is a perfect example of how the stigma associated with sexuality gets played out [and] acts as a barrier to this young man's ability to access social support services.

After a person tests positive, he or she faces decisions that include how to obtain and adhere to medical care and whether to disclose HIV seropositivity to partners, friends, family, colleagues, employers, and health care providers.⁸ At each level, a decision to disclose seropositivity may either enhance access to support and care or expose the person to stigmatization and potential discrimination. Among YMSM of color, the decision to disclose can be a frightening proposition, as one outreach worker pointed out:

Being an HIV-positive youth of color presents multilayered and complicated barriers. Supposed friends outing friends' HIV status can cause young people to be ostracized by their

peers and/or can push youth to isolate themselves: "He's contaminated goods." Access once granted into social circles may be severed once you become positive and everyone is talking about you behind your back, sometimes even in your face. This may cause HIV positive youth . . . to feel they cannot disclose their status to their partners for fear of being outed, putting themselves and their partners at risk for more infections. "I'm positive now, what else do I have to lose?" "If I tell this person I am positive, they will not want to have sex with me."

Impact on Subgroups

In the YMSM project, outreach workers often observe the effects of stigma on certain groups' access to care, particularly for transgendered clients and substance abusers:

Trans people are severely lacking in accessing routine health care. One of the major reasons is the level of homophobia/transphobia among medical providers. Finding a doctor with experience in trans health is [like] searching for that famous needle in a haystack. Moreover, trans people are highly stigmatized and/or stereotyped as mentally handicapped, lower members of society and, at times, as outcasts.

Substance users might purposely not access services for fear of being preached to about said substance use, a fear of being judged by providers, or worse, a fear of incarceration or forced rehabilitation. Sometimes substance users will lie about their use . . . and that can become a barrier in accessing support services.

Finally, stigma from being "outed" as HIV positive can have consequences that go well beyond having to find new friends or health care providers. One outreach worker observed the following situation:

Take the example of a 20-year-old Latino client of ours. His family is working on receiving their documentation for political asylum; however, this young man is filing separately, unbeknownst to his family. . . . Since he is MSM and HIV positive, he has a strong case for asylum. He has not informed his family about his sexuality or his HIV status for fear of being rejected by them and sent back to his birth country.

Strategies for Addressing Stigma

How do peer outreach workers accomplish their goals in an environment of stigma? Of course, treating members of the target populations with dignity and respect can help counter internalized negative messages. Outreach workers offered a variety of specific ideas for mitigating the effects of stigma on clients' willingness to seek and stay in care:

Working With and Retaining Clients

- Know thyself: Providers need to be aware of their own biases because they will interfere with their ability to work effectively with clients.
- Be nonjudgmental: Neither condemn nor condone a person's behaviors.
- Focus on risk reduction. Find out what a client is doing and give him information on how to do it safely or mitigate the effects.
- Work to establish trust with clients, and demonstrate that staff are able to help them; otherwise, clients may be reluctant to return for services.
- Meet people where they are, and help them move forward step by step.
- Shape solutions to individual circumstances.
- Listen carefully to clients to find out what behaviors they are engaging in and why. Make no assumptions.
- Identifying shirts or badges can be a drawback, because some clients will avoid being seen talking to an outreach worker.
- Sometimes computerized surveys are more effective than personal interviews in assessing risk because people tend to be more honest when answering questions on a computer.

Facts About HIV and YMSM

- In the United States, half of all new HIV infections are believed to occur in people under age 25; one-fourth occur in people under age 21.¹
- In 2002, 28 percent of all new diagnoses of HIV/AIDS were among 25- to 34-year-olds.²
- Of the cumulative AIDS cases in 13- to 19-year-olds, 51 percent are among African-Americans and 20 percent are among Hispanics.³
- Between 1998 and 2002, AIDS incidence increased by 16 percent among youth ages 13 to 24.⁴ Given the time from seroconversion to progression to AIDS, which often spans 10 years or more, it is evident that a large portion of AIDS cases reported among people under age 30 resulted from HIV infection contracted in their teens.
- Young people may be more vulnerable to HIV/AIDS than older people. Their social, emotional, and psychological development is not complete. Therefore, they have a tendency to experiment with risky behavior and alcohol and drug use.⁵
- Several risk factors are associated with a higher risk for HIV among youth. For example, 1 in 7 adolescents in the United States live in poverty, 1 in 2 minority adolescents live in poverty, and nearly 5 million adolescents are uninsured.⁶

¹ Office of National AIDS Policy. *Youth and HIV/AIDS: 2000 A New American Agenda*. Washington, DC; 2000.

² CDC. *HIV/AIDS Surveillance Report*. 2002;14:6.

³ CDC. *HIV/AIDS Surveillance in Adolescents*. L265 slide series (through 2001). Slide 7. Available at: www.cdc.gov/hiv/graphics/adolesnt.htm.

⁴ CDC. *HIV/AIDS Surveillance Report*. 2002;14:12. Table 3.

⁵ Ellen JM. Adolescents and HIV. *The Hopkins AIDS Report*. 2002; May.

⁶ Ryan C, et al. Adolescent health challenges: lesbian and gay youth care and counseling. *Adolescent Medicine, State of the Art Review*. 1997;8(2):208-10.

Working With Transgendered Populations

- Educate outreach workers about the challenges of being transgendered.
- If the outreach worker is not part of the targeted community, some clients may feel more confident that their case will remain confidential.
- Make no assumptions; ask clients how they want to be identified.

Conclusion

The SPNS YMSM Initiative ends in 2009, at which time the Evaluation Center will assess which models best address the challenges YMSM face in decreasing risk behaviors. In the meantime, the peer outreach workers will continue to refine their work in countering the effects of stigma and learning what works to bring YMSM of color into medical care.

Endnotes

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